

Chronic Urinary Retention and Fowler's Syndrome



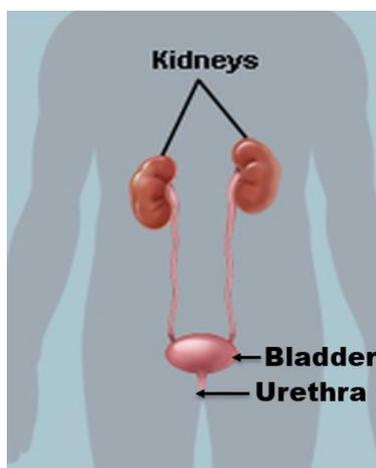
FACTSHEET

What is Chronic Urinary Retention?

Chronic Urinary Retention is when your bladder fills up and you can't pass urine at all, or you can only do a little, leaving a lot of urine behind in the bladder.

There are many causes of chronic urinary retention such as problems with the prostate gland in men or narrowing of the urethra, both of which restrict the outflow of urine from the bladder. In addition, neurological diseases affecting the spinal cord may cause paralysis of the bladder.

In many people though, and especially women, Chronic Urinary Retention can happen for reasons that are more complicated and harder to see with tests. In this factsheet we use the term 'Chronic Urinary Retention' to describe this situation. Sometimes the terms 'Chronic Idiopathic Urinary Retention' or 'Chronic Voiding Dysfunction' are used. You may have been told you have an 'atonic bladder'.



We are still learning about Chronic Urinary Retention and we don't have all the answers.

This factsheet is designed to help share what we *do know* about this condition and to give you some ideas to help make sense of what has happened.

It will also describe Fowler's syndrome which is a cause for Chronic Urinary Retention in some women.

Since most patients with this problem are women, we will refer to women in the rest of this factsheet.

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What are the symptoms of Chronic Urinary Retention?

The main problem is being unable to pass urine. There may be pain because the bladder is full and distended (stretched) but there is often not as much of a sense of 'bursting for the loo' as you might expect.

Some women can't pass urine at all - this is called *retention*. Some can pass urine a bit but with difficulty and don't empty their bladder – this is called incomplete bladder emptying.

Usually it doesn't help to strain to try to empty the bladder

Because it is so hard to pass urine, most people with Chronic Urinary Retention need to have a catheter (tube) to help them pass urine.

Many women have a history in the past of 'voiding dysfunction' – not being able to pee properly with trouble 'getting started' and an interrupted flow when they then do. Some may have got in to habit of 'holding on' rather than going to the loo when their bladders were full. It may have been present but not bad enough to see a doctor about. Some women are probably just 'put together' that way, which makes them vulnerable to Chronic Urinary Retention

What triggers can lead to Chronic Urinary Retention?

- **Medications** - There are many types of medication that can worsen 'voiding dysfunction'. These often seem to 'add in' to the picture and trigger retention in someone who is already vulnerable. They include:
 - **Opiates** – such as tramadol, codeine, oxycodone or morphine
 - **Antidepressants** – including amitriptyline and imipramine
- **Operation/ Anaesthesia** - In many women with Chronic Urinary Retention the problem begins after a surgical procedure. Typically, this is a urological (e.g. cystoscopy) or gynaecological (e.g. hysterectomy) operation or an obstetric intervention to aid childbirth (e.g. Caesarean section). Sometimes it develops after an operation elsewhere. Any operation where a urinary catheter is used can be a trigger, so it may be something to do with the anaesthetic itself. Anaesthetics can make people feel "dissociated". This is the medical word for feeling disconnected from your own body or from the world around you.

In addition, patients with Chronic Urinary Retention are much more likely to have chronic pain or a functional neurological disorder (described at www.neurosymbols.org) than the rest of the population. The reason for this is unclear and is an area that is being researched. Some of this may be the distress of the condition but it could also be that there are shared reasons why these conditions, all of which relate to a 'software problem' in the nervous system – may group together.

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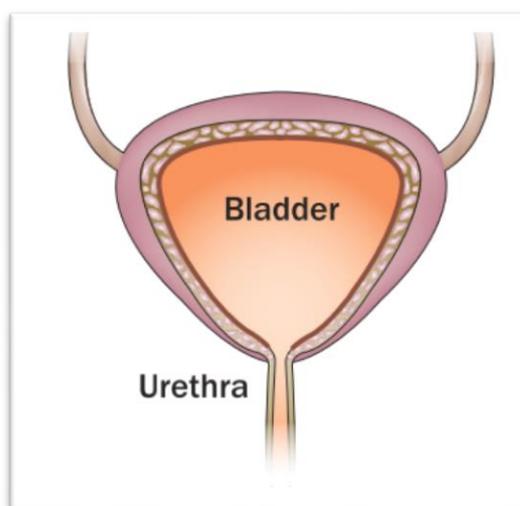
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How is the diagnosis made?

The diagnosis is normally made by a Urologist, Uro-gynaecologist or Uro-neurologist who will first look for other causes of retention such as something physically blocking the neck of the bladder, or a neurological disease such as a large disc squashing all the nerves supplying the bladder (cauda equina syndrome).

There are some common tests that are done to look at the problem in more detail. Some of them are uncomfortable and if you are reading this, you may already have had one or more of them

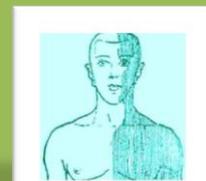
- **Urodynamics** – This involves measuring the pressure inside the bladder as it fills and looking at how it works when you are trying to pass urine. When this is combined with x-rays it is called video urodynamics.
- **Bladder Ultrasound** – can see how much urine is left in your bladder after you try to pee
- **Cystoscopy** – is a camera test done to look inside the bladder for any problems



Some other more specialised tests that are sometimes done are

- **Sphincter EMG (Electromyogram)**. This records electrical activity in the urethral sphincter. This is the circular muscle that surrounds the opening to your bladder.
- **Ultrasound of the sphincter** – this can help measure the size of the sphincter which may help work out what has gone wrong
- **Urethral pressure profile** – this test measures the pressure in the water-pipe (urethra) sphincter muscle, as a catheter is inserted and withdrawn several times.

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Fowler's Syndrome – a disorder of urethral sphincter relaxation

In the past many women with urinary retention were dismissed as having nothing wrong with them and received no treatment.

In the mid-1980s, Professor Clare Fowler, a neurologist in London found that around one third of the women with chronic urinary retention also had abnormalities on some of these specialised tests. In particular, she found that the EMG test described above showed an abnormal pattern of activity. The pictures below show this.



Professor Clare Fowler CBE



This is a normal sphincter EMG



This EMG shows an abnormal pattern of sphincter muscle activity

All of this suggests there is a *disorder of muscle relaxation*, the urethral sphincter is gripping too tight and won't let go.

Most women with this condition are in their twenties and thirties. Typically women will present with urinary retention of more than a litre however may not be desperate to go to the loo as one might expect. When catheterising, many women report a sense of 'gripping' around the urethra when removing the catheter, like it has gone in to spasm. Some women with Fowler's Syndrome may have polycystic ovaries.

“There is a disorder of muscle relaxation, the urethral sphincter is gripping too tight and won't let go”

Professor Fowler also showed that a treatment called Sacral Neuromodulation, could help some women with Chronic Urinary Retention to regain bladder function.

“But I just have retention. I haven't been diagnosed Fowler's Syndrome, or had that EMG test – what is wrong with me?”

Most women with Chronic Urinary Retention don't have clear cut Fowler's syndrome, but they still have all the same symptoms. The symptoms and triggers, like operations and medication, are the same to women with Fowler's syndrome and the approach to treatment is often similar. It may well be that the conditions are very similar.

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Let's look at a typical history of someone with Chronic Urinary Retention

Lisa is a 27-year-old woman who was in hospital having an operation called laparoscopy (a camera test just looking around inside the abdomen and pelvis) to investigate some pelvic pain that she had experienced over the previous 6 months. The surgeons didn't find any structural explanation for her severe pain.

When she came round from the procedure her pelvic pain was worse, and she remembered feeling much more "spaced out" than she had after previous anaesthetics. The pain and wooziness were quite scary and she also felt really frustrated that the doctors hadn't been able to find out the cause of her pain. Lisa was given some morphine to settle her pain.

That night in the ward she found that she couldn't pass urine. Lisa tried really hard and the nurses encouraged her, but nothing came out. A catheter was put in. The following day when the catheter was taken out she still couldn't pass urine normally, so it had to be put back in.

Over the subsequent few months Lisa saw specialists who couldn't work out why she was in chronic urinary retention. She learnt how to use intermittent self-catheterisation although found that uncomfortable. Her pelvic pain continued, and she had been put on various medications including tramadol (a painkiller). She had other problems too including low back pain, sleep problems and excessive tiredness. On one occasion she had experienced weakness of one her legs which had been frightening – although it had improved again.

Lisa had a cystoscopy which showed that the bladder and urethra looked normal. At one point the doctors had been worried about a neurological disease but an MRI of her spine and brain were normal. She also underwent some more specialised tests to see if she had Fowler's syndrome but the results of those weren't conclusive.

She now felt at her wits end. Why had her bladder stopped working? Why couldn't the doctors find out what had gone wrong? And what could be done about it?

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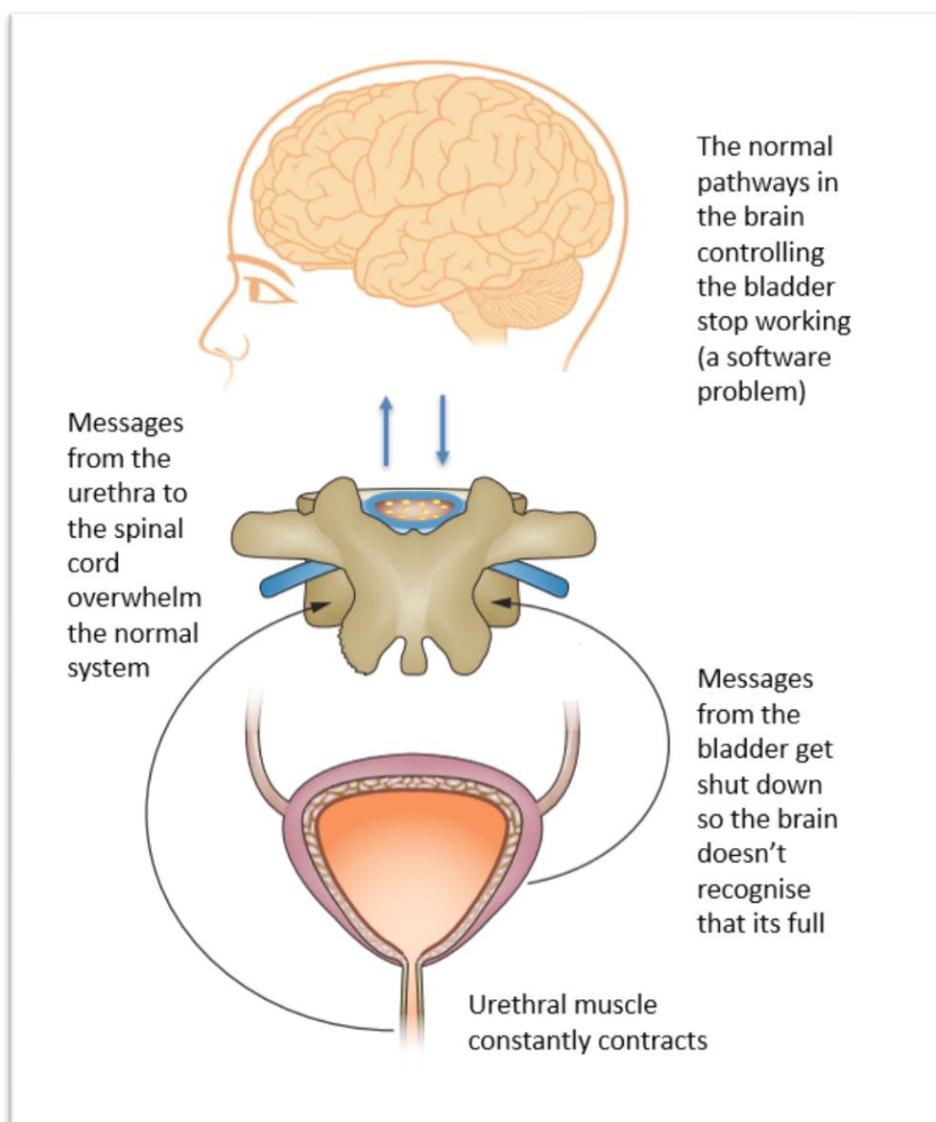
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What causes Chronic Urinary Retention?

In roughly 40% of patients, chronic urinary retention happens in the absence of an obvious structural/surgical cause or a neurological condition. We are still figuring things out, but we do have some ideas about what is going wrong. Chronic Urinary Retention in this scenario, it's likely to be a combination of a problem in the bladder *and the brain*.

The urethral muscle contraction may “turn the volume knob up” on messages back to the brain and spinal cord. This overwhelms the normal system that keeps tabs on what happens in the bladder. Messages from the bladder don't get received properly to activate it to contract.



Adapted from Osman N, Chapple C. Nature Reviews Urology 2014 with permission

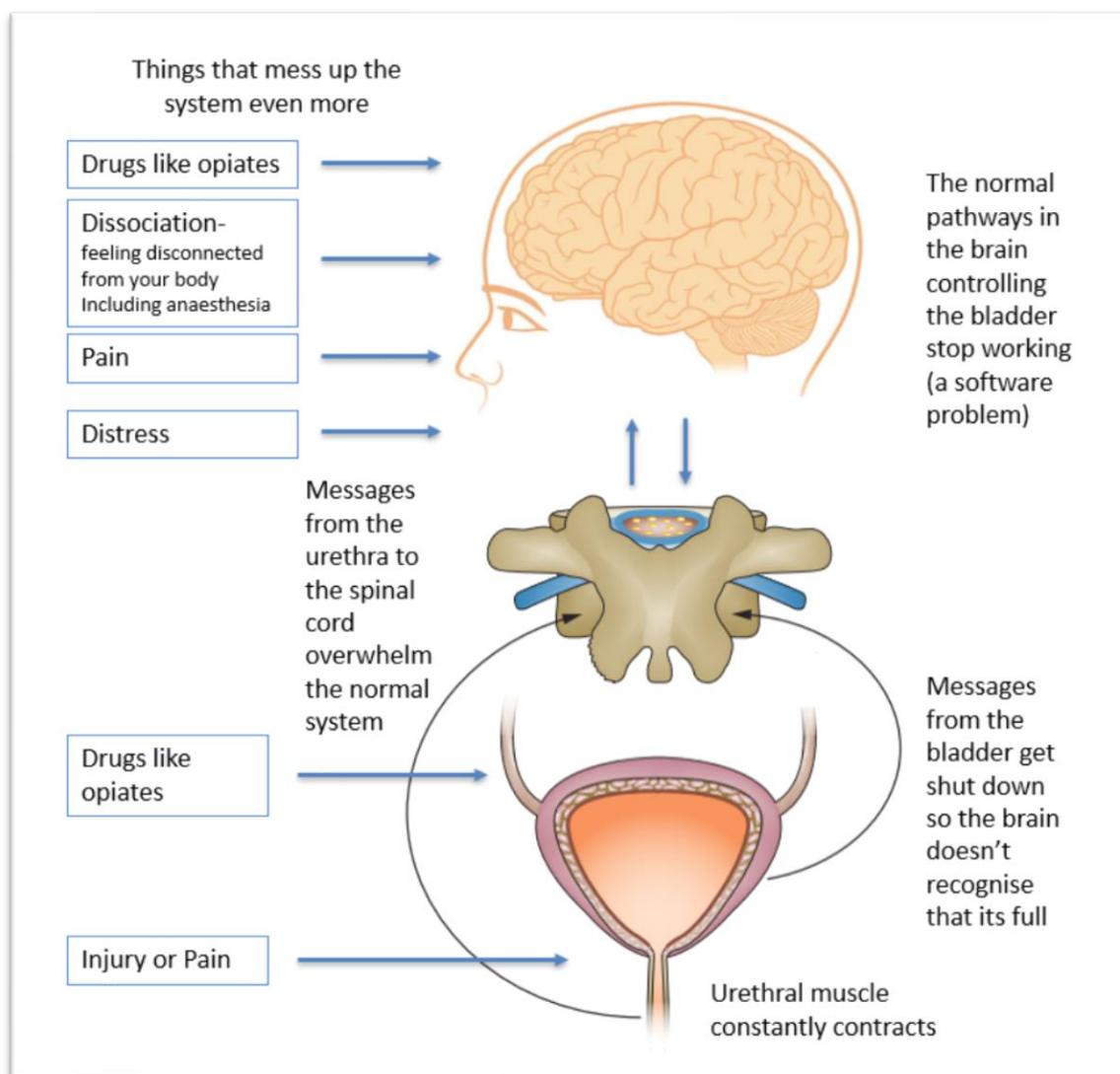
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What things make it worse?

The picture below shows how other things that can trigger Chronic Urinary Retention end up making the problem worse and maintaining it. These things act at all levels from the bladder to the brain



Adapted from Osman N, Chapple C. Nature Reviews Urology 2014 with permission

We don't have all the answers, but we have enough to begin to work on the problem. It's really important that you as a patient, feel you have some idea of what has gone wrong. Ask a health professional to help you work through this explanation, as understanding it could help you with further aspects of treatment.

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What is the treatment?

Do you have confidence in the diagnosis?

It is essential that you feel that you have the correct diagnosis. If you don't it will be hard to put into practice the rehabilitation techniques suggested here.

It is hard getting your head round this problem – especially when it's hard to see on tests.

If you don't feel that you have Chronic Urinary Retention you need to look at what basis the diagnosis has been made. You should have some of the clinical features described above. If you do, why don't you have confidence in the diagnosis you have been given? Talk to your doctors if you lack confidence in the diagnosis.

Catheterisation

A catheter, of some sort, is usually unavoidable in Chronic Urinary Retention.

Your Urology service and continence advisor will tell you more. Most women prefer Intermittent Self Catheterisation (ISC) which is used in many neurological conditions as well.

Reducing exacerbating factors

Looking at the picture on the last page you can see that it is helpful to minimise anything that might be making it worse, where possible. This may include

1. **Reducing or changing medication** that may be worsening the retention – especially opiates.

DO NOT CHANGE YOUR MEDICATION WITHOUT DISCUSSING WITH A DOCTOR.

2. **Better pain management** – if pain, especially back pain, is making things worse. This may have to involve rehabilitation techniques from a pain service including physiotherapy and psychological pain therapy.

Sacral Neuromodulation

This is an operation where a small electrical stimulator is implanted in your lower back. This provides electrical impulses to the nerves that supply the bladder and can help correct the imbalance in the nervous supply described on the last page. It is not suitable for everyone and many patients don't benefit from test stimulation.

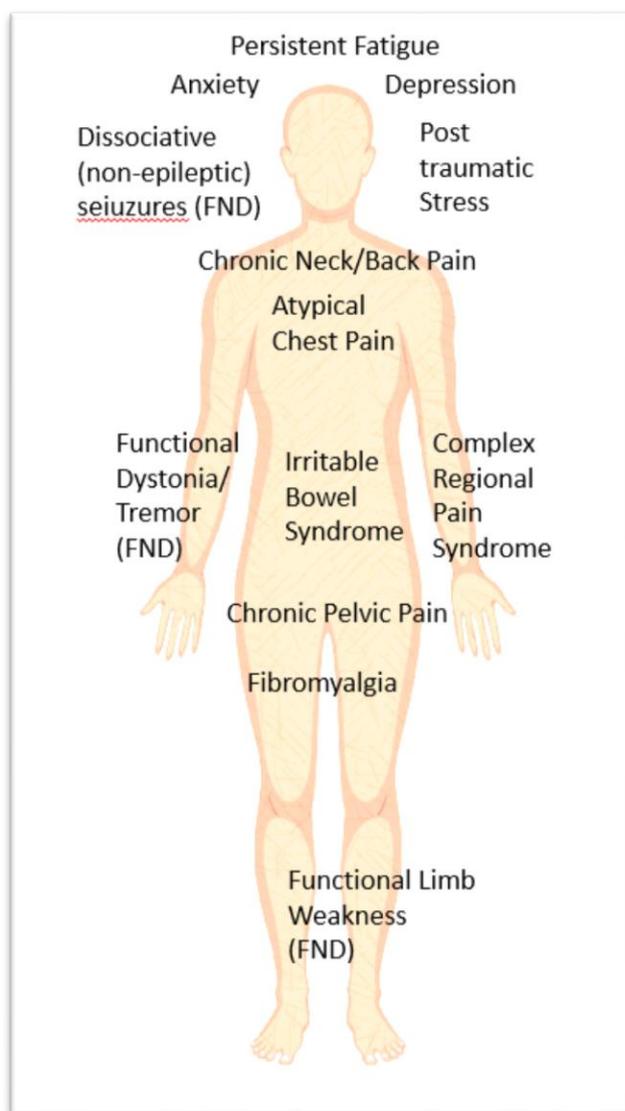
Look on www.fowlersyndrome.co.uk to find out more.

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Looking at the bigger picture

In the last few years some doctors have become more interested in how chronic urinary retention may be part, in some patients, of a 'bigger picture' of ill health.



Research has shown that women with chronic urinary retention have higher frequency of other physical health problems, especially chronic pain and functional disorders. Functional disorders are common conditions which, like Chronic Urinary Retention, relate to abnormal functioning of the nervous system rather than nerve damage (software not hardware).

Functional disorders include irritable bowel syndrome, fibromyalgia and Functional Neurological Disorder (FND) where there may be limb weakness, tremor, spasm or seizures.

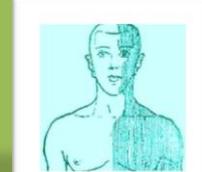
Psychological problems such as depression, anxiety and post-traumatic stress also seem more common, although more research is needed and some of that may relate to the stress of the condition itself

There are **plenty of women with NONE of these other health problems** so please don't be put off if this section doesn't apply to you.

But if it does, it may be worth spending time with a health professional, such as clinical psychologist, neurologist or psychiatrist who understands these disorders to try and put things together for you. It may be that having a functional disorder is one of several vulnerabilities that in some way can relate to chronic urinary retention, however further research is required.

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What is likely to happen to my urinary retention?

This depends on:

- how severe the problem was in the first place
- whether there were medications making it worse which can be stopped.
- whether you are a candidate for sacral neuromodulation
- whether other therapy described above can help

There is no getting away from the fact that for some women Chronic Urinary Retention, as the name suggests, can be a long-term condition.

But, it can also be something that some women do learn to live with and manage, and in some cases may improve over time.

We really need a lot more research in to this condition. We hope this factsheet has helped a little to help you understand it a little more.

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Further information



www.fowlersyndrome.co.uk

Has a lot of information on Fowlers syndrome including scientific references.



www.neurosymbols.org

explains more about functional disorders and functional neurological disorder (FND) in particular, if that is relevant to you.